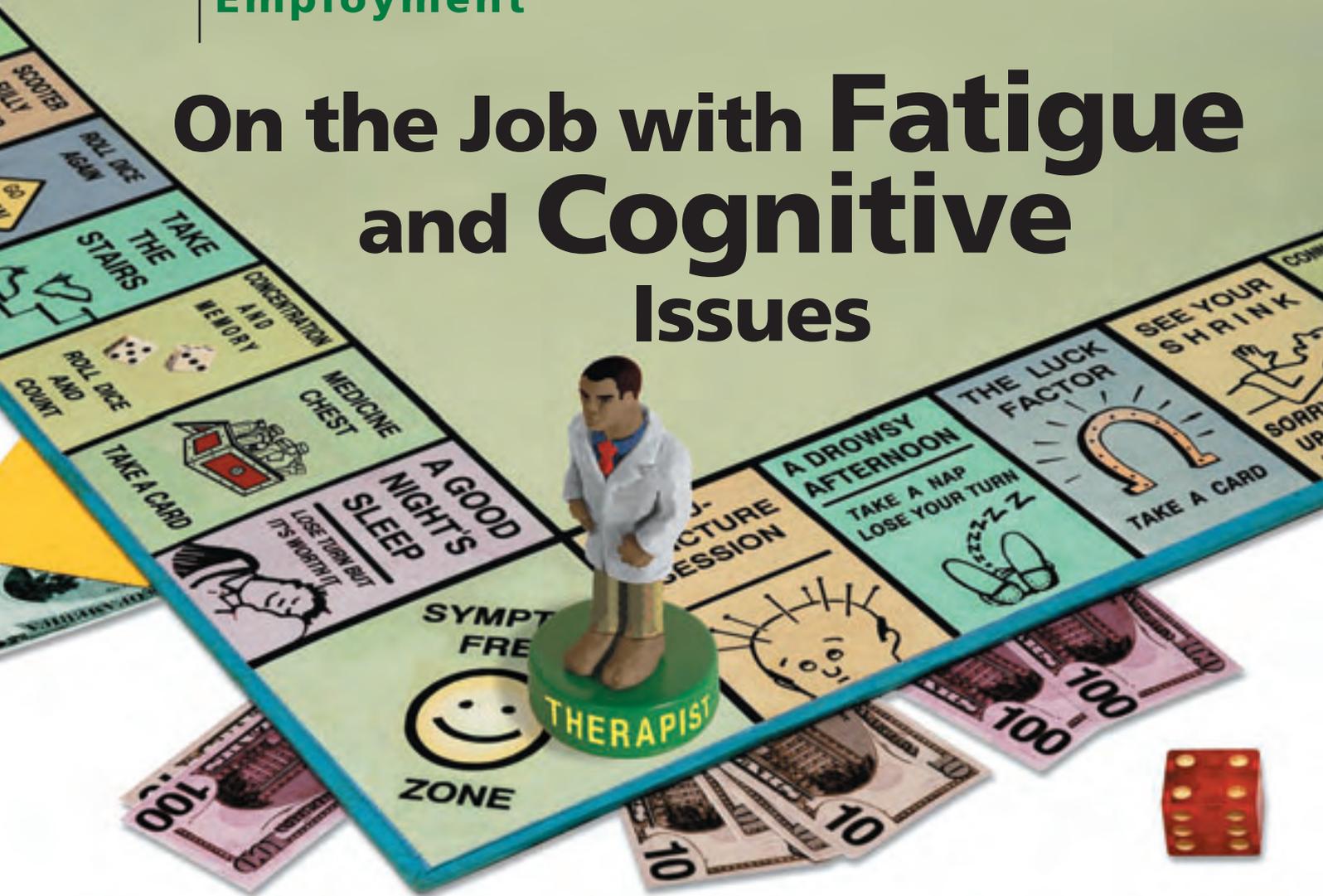


# On the Job with Fatigue and Cognitive Issues



B Y J O S T R A T M O E N

**F**atigue and cognitive issues—not physical disability—are the major reasons why many people with MS eventually leave the workforce. Up to 87% of people with MS report significant fatigue. Cognitive dysfunction affects 45%–65% of people with MS.

Fatigue can increase cognitive problems. So can stress. If not addressed, they may combine into a downward spiral.

## Strike one: fatigue

If you have MS, you probably know what dragging yourself out of bed to get to work feels like. But, Susan Forwell, PhD, an occupational therapist with the School of Rehabilitation Sciences at the University of British Columbia in Canada, echoes

most experts when she says the causes of fatigue in MS are poorly understood.

“Some researchers believe fatigue is a direct consequence of the disease process while others suggest that it is also a factor associated with mobility problems, depression, and sleep disturbances,” Forwell said. Moreover, research is hobbled because there are no truly objective measures of fatigue. It is hard to tease out the factors that go into a person’s perceptions of his/her fatigue—and just as difficult to verify the outcomes of treatment.

*“The more tired I get, the more stressed I get and the more I find it hard to concentrate and the more tired and stressed I get. It’s a vicious circle.”*

### **Cytokines and axons: connections not proved**

One mechanism of the disease process is the elevation of pro-inflammatory proteins called cytokines. In experiments, these cytokines trigger fatigue and sleepiness. Another mechanism is a loss of axons, the nerve fibers that conduct impulses through the central nervous system. Axon loss is associated with higher levels of disability. But, so far researchers have not been able to show that either elevated levels of pro-inflammatory cytokines or higher degrees of disability are always connected to higher levels of fatigue in MS.

### **Problems with mobility, sleep, or depression**

Having any mobility problem increases fatigue. People with disabilities spend a lot of energy negotiating daily tasks. Depression shares some common attributes with fatigue, such as lack of energy and decreased motivation. “And sleep problems result in some of the same symptoms,” Forwell said.

But once again, researchers cannot be certain that depression or sleep problems correlate strongly with the level of fatigue.

### **What to do**

Clearly, getting a handle on fatigue is an ongoing process. Each person has to uncover the strategies that help her or him. Moreover, the degree to which a person can manage

fatigue in the workplace depends on the type of work the individual does.

“Those who work in offices have a better chance of being able to reconfigure their workspace and workload to accommodate their fatigue,” Forwell said. “Avoiding stairs, taking regular breaks, and having a comfortable place to rest from time to time can help a lot.” Energy conservation techniques, shown in the table on page 26, may be essential. Maintaining physical fitness also decreases fatigue so an exercise program is equally important.

“Unfortunately, some jobs require people to be on their feet all day. They cannot

practice energy conservation,” Forwell noted. “I advise them to try and switch to a job within the same industry that allows them to sit and take regular breaks.”

### **First seek medical help**

Check with your doctor if you habitually start the day feeling unrested or have symptoms of depression. Ask if any of your medications could be contributing to your fatigue. Ask about any herbs or dietary supplements you use as well, because some of them increase fatigue.

### **Then seek therapists who specialize in job retention**

An occupational therapist can help develop strategies for performing daily activities at work and at home.

A vocational rehabilitation specialist can offer solutions such as redesigning a workspace or identifying other more suitable jobs. The Rehabilitation Services Administration, a federal agency, supports vocational rehabilitation programs in every state. Services may include funding for training, home or workplace modifications, and assistive technology to help people with disabilities obtain or maintain work. To contact your state’s vocational rehabilitation program, go to [www.jan.wvu.edu](http://www.jan.wvu.edu) or telephone 800-526-7234 toll-free.

### **Do medications help?**

This is a controversial area as no one medication clearly works well for everyone. According to Dr. Forwell, modafinil (Provigil) is the most useful agent available at the moment. This conclusion has

come under scrutiny, as indicated in the box on page 29. Amantadine (Symmetrel) has demonstrated a modest benefit on MS fatigue and is much less expensive than modafinil. Both fluoxetine (Prozac) and bupropion (Wellbutrin) may be helpful.

### **Strike two: cognitive problems**

You’re at your desk working on a spreadsheet program and someone stops by to talk about last night’s baseball game. This brief interruption is

#### **Energy conservation techniques**

- Prioritize tasks
- Plan ahead (schedule strenuous tasks throughout the week, not all at once)
  - Perform the most strenuous task during the part of the day when you have the most energy
  - Take a 10-minute break every hour
  - Pace yourself
  - Perform activities while sitting, when possible
  - Organize your workspace to avoid reaching, bending, carrying, and climbing
  - Use labor-saving techniques (for example, if you need to get a file from somewhere else try to wait until you have several files to collect)
  - Plan on 10 to 12 hours of daily rest
  - Use correct body mechanics (your physical therapist will help you identify and implement these)



enough to derail your entire train of thought. You have to go back and start again. The impact of MS on cognition can make the simplest task into a complicated mental hurdle.

According to neuropsychologist Lauren Caruso, PhD, people with MS exhibit varying degrees and types of cognitive problems depending on where lesions are seen in their brains and whether atrophy, or loss of volume in the brain, has occurred. Magnetic resonance imaging (MRI) studies have helped clarify why many people with MS experience cognitive dysfunction.

“The most common problems to affect performance on the job are problems with attention, concentration, and short-term memory,” Dr. Caruso said. It may become difficult to concentrate on two things at once. The ability to multi-task or think on your feet may diminish. Prioritizing thoughts, moving smoothly from topic to topic, or controlling the expression of emotions may become impaired.

In addition, some cognitive problems affect vision or communication. Dr. Caruso noted, “It is sometimes difficult for people with MS to recognize the relationship between objects that they see, or

to find the right word to express what they want to say.”

While these are correctly called **cognitive** problems, they don't affect **intellectual** function. Most people with MS are able to reason, learn, draw from their knowledge and experiences, and make appropriate conclusions and judgments.

### What to do

General tips for cognitive issues are listed on page 27. These ideas may also help:

For better concentration, ask to have a private office or a workstation separated from the rest of the gang.

### Cognitive strategies

- Write everything down: diaries, loose-leaf organizers, and hand-held computer/organizers are helpful.
- Have a particular place for everything and always put things back where they belong; encourage others to do the same.
- Repeat things that need to be remembered. And write them down.
- Try not to get hung up on recalling a word. People are often happy to chime in with the right one. Let them.
- Take your time. Plan your work and don't be rushed by anyone.
- If you find cognitive problems crop up at a particular time of day, reorganize activities so you have the more demanding things done before that time.

When working on a complicated task, switch the phone to voicemail and turn down the volume on the computer to limit interruptions or disturbances.

Avoid situations where quick mental processing is required. Help your employers and colleagues to understand that you might not think as quickly as you used to but this doesn't mean that you can't think effectively when given time.

Work on being well organized. According to Dr. Caruso, this can go a long way

## Two ways to protect your future

**One:** Act early to protect your job if you know you are developing cognitive problems. Carefully prepared disclosure may be in your best interest. People with hidden cognitive problems may end up fired—and people who are fired are not eligible for unemployment benefits or disability insurance coverage.

**Two:** Be aware that flexible schedules are not the same as reduced work hours. Flextime should add up to a full work week. If you opt for part-time work and retire altogether at a later date, your disability benefits will probably reflect your most recent earnings. Be very sure you know how your benefits would be affected should you reduce your hours or accept a lower paying, less stressful job. Have a candid conversation with your benefits manager before telling your employer what you plan to do.

to dealing with cognitive problems in the workplace.

Get adequate sleep. "Cultivating regular sleep patterns is one of the most important things to do to moderate cognitive problems," Dr. Caruso believes.

Professional help can make a difference. Neuropsychologists are experts in evaluating cognitive problems and developing compensating strategies for them. Occupational therapists and speech/language pathologists also have expertise in cognitive problems. Your MS health professional or Society chapter can provide referrals.

## Alternatives?

People try a variety of complementary therapies to alleviate cognitive problems or to address side issues, such as stress, that make the problems more intense. Discuss any herbal or dietary supplement or other alternative treatment such as acupuncture with your MS health professional first. You should expect your MS professional to listen to your ideas and give you valuable insights. Practices such as yoga and meditation are known to help many people.

## You're still in the game

While fatigue and cognitive problems caused by MS can have a major impact on the ability to work, every individual is different. Explore what works for you in order to learn what accommodations could contribute to your personal job performance. Look for strategies that compensate for your particular problems.

Keeping your job may feel like a full-time job in itself. Only you can know if



the effort continues to be worth the result. You should know that many people with MS continue to work for many years, thanks to their determination, some good luck, and the help of knowledgeable professionals.

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Jo Stratmoen wrote about myelin repair and protection research for **InsideMS** last October-November.

### References for your health-care professional

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### Mixed messages about Provigil for MS fatigue

Provigil has been used to treat excessive sleepiness caused by certain sleep disorders since 1999. In 2000, the manufacturer, Cephalon, conducted a study to evaluate its effect on fatigue in MS. The findings stated that people taking Provigil reported less fatigue compared to people taking a placebo. Two small, subsequent studies reported similar findings.

Physicians began prescribing Provigil, off-label, for MS fatigue. Since there were no serious side effects, it seemed safe to give it a try. However, a rigorous controlled trial in 115 people with MS, published in the April 2005 issue of *Neurology*, concluded that there was no improvement of fatigue in people treated with Provigil compared to people taking an inactive placebo.

The investigators suggest that “placebo effects” may have contributed to the positive results of earlier studies. But many respected clinicians who treat people with MS, including several who reviewed this article, are impressed with the positive effects of Provigil on MS fatigue. They are mainly dismayed by its high cost. The researchers acknowledge that further studies are needed before firm conclusions can be made about this drug.

—*Rochelle Kraut*